



Australian women's experiences of living with gestational diabetes



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ABSTRACT

Purpose: The purpose of this study was to describe Australian women's reflections on the experience of having a pregnancy affected by GDM.

Methods: Participants were women aged ≥ 18 years, diagnosed with GDM ≤ 3 years previously and registered with the National Diabetes Services Scheme. Data was collected from a cross-sectional written postal survey which included the opportunity for women to document their experiences of living with GDM. Thematic framework analysis was undertaken to determine underlying themes.

Results: Of 4098 invited eligible women, 1372 consented to participate. Of these, 393 provided feedback on their experiences of living with GDM. Eight key themes emerged from the data (1) shock, fear and anxiety (8.9%), (2) uncertainty and scepticism (9.4%), (3) an opportunity to improve one's health (9.6%), (4) adapting to life with GDM (11.6%), (5) the need for support (17.2%), (6) better awareness (3.5%), (7) abandoned (14.9%), (8) staying healthy and preventing diabetes (13.7%). Women taking insulin were more likely to experience shock, fear or anxiety ($p = 0.001$) and there was a trend towards women who spoke another language also being more likely to report this experience ($p = 0.061$). Those diagnosed with GDM in a previous pregnancy ($p = 0.034$) and younger women ($p = 0.054$) were less likely to view the diagnosis as an opportunity to improve their health.

Conclusions: This study provides an insight into the experience of the pregnant woman diagnosed with GDM. It emphasises the importance of health professional support and provides insight into the challenges and opportunities for future diabetes risk reduction.

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1. Introduction

Gestational diabetes mellitus (GDM) is a form of diabetes with onset or first recognition during pregnancy.¹ GDM affects approximately 5% of pregnancies in Australia, increasing up to 14% in some high risk groups.² With evidence suggesting that rates of GDM are currently increasing in Australia,² it is important for health professionals to understand the impact of the diagnosis and the experiences of women living with GDM. This can help identify priorities for health care provision and inform interventions to meet the needs of women with GDM.

GDM has been demonstrated to pose perinatal risks³ as well as adverse maternal health consequences including an increased risk

of future type 2 diabetes.^{4,5} Treatment of GDM may lower the risk of birth complications,⁶ however this requires intensive ante-natal interventions and day to day self-management to achieve optimal glycaemic control.¹

Some evidence suggests that a diagnosis of GDM may increase a woman's anxiety,⁷ result in poorer health perceptions and a less positive pregnancy experience when compared with non-diabetic controls.⁸ A Canadian study described the experiences of women diagnosed with GDM as living a controlled pregnancy, followed by a process of adaptation to the diagnosis, while burdened by the moral obligation to be a responsible mother and being worried about potential impact on future health.⁹ Similarly, Nolan et al. (2011) in research with US women with GDM and type 2 diabetes identified three primary themes related to concern for the infant, concern for self and sensing a loss of personal control over their health.¹⁰ Research with Swedish women described the diagnosis as a process of 'stun to gradual balance', where both positive and negative elements were reported.¹¹

Several Australian studies to date have provided some insight into the experiences of women with GDM. Carolan (2013) using

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focus groups and semi-structured interviews with 15 women with GDM, examined women's experiences with diabetes self-management.¹² In the process of adjusting to GDM, they described four discrete themes, relating to the shock of diagnosis, coming to terms with GDM, working it out/learning new strategies and looking to the future. Each adjustment phase was underpinned by the fifth theme of having a supportive environment. Adherence to the GDM management plan was reported to be motivated by thinking about the baby. In a study examining factors that facilitate or inhibit GDM self management in Australian women, time pressures, physical and social constraints, comprehension difficulties, and insulin as an easier option were described as barriers to self management. Thinking about the baby and psychological support from partners and families were facilitators.¹³ In telephone interviews with 57 women with previous GDM, Razee et al. (2010) highlighted a number of social and cultural barriers influencing their ability to follow a healthy lifestyle in the post-natal period.¹⁴ Doran (2008) examining perspectives on lifestyle changes in interviews with eight Australian women also reported a lack of support for post-natal risk reduction.¹⁵ While these studies provide an insight into women's experiences, the samples were drawn from health service based data sets which may limit the generalisability of the results.

The aim of our study was to build on these findings by describing Australian women's reflections on the experience of having a pregnancy affected by GDM in a large sample of women from a national gestational diabetes register. A secondary aim was to describe associations between the characteristics of respondents and their GDM pregnancy experience.

2. Subjects and methods

This study was a mixed methods study with data collected from a cross sectional survey of Australian women with a recent history of GDM. Participants were recruited from the National Diabetes Service Scheme (NDSS) database. The NDSS is an initiative of the Commonwealth Government providing subsidised diabetes self-management products to Australian residents with diabetes registered with the scheme. All registrants have the option of consenting to being contacted for research purposes. Study inclusion criteria were: diagnosed with GDM ≤ 3 years previously, registered with the NDSS and consented to be contacted for research purposes. Women were excluded if they were aged < 18 years at the time of registration database or resided in a Queensland postcode because of a concurrent study of gestational diabetes being undertaken in that state. The University of Newcastle Human Research Ethics Committee approved the study and Diabetes Australia Ltd. approved and conducted the NDSS database search. All potential participants were contacted by mail, with eligible women sent a letter of invitation, a participant information package, a written survey, a reply paid envelope and a pen. A reminder postcard was sent to all eligible women 1 month after the initial mail-out. Data from the 15,893 women registered on the NDSS during the same period was used to determine whether respondents differed from those who did not consent to be contacted for research purposes or did not participate.

The survey was a self-administered written questionnaire with 69 predominantly closed questions. Briefly, survey questions addressed demographics, educational attainment, language spoken at home and occupation using standard items from the 2001 Australian census.¹⁶ Information regarding GDM management, lifestyle-related risk factors, family and medical history, and postpartum follow-up were collected by self-report. Respondent's height and pre and postpartum weight were self-reported. Physical activity and diet quality were assessed using validated tools. The self-administered questionnaire was pilot tested with a convenience sample of women ($n = 23$) from the Diabetes Australia-NSW

membership database. At completion of the closed questions, women were provided with an optional open ended question allowing them to document their experiences of living with GDM using free text narrative. This text provided the qualitative component of the survey and an 'open forum' for women to describe their unique experience in the absence of structured or pre-determined questions.

3. Data analysis

The analysis of open ended responses content involved systematically classifying narrative into themes. The framework approach was the method chosen to underpin data analysis because of its suitability for analysis of cross sectional data and because of the systematic approach it provided for the analysis of a large number of written responses.¹⁷ Analysis involved a deductive approach which included initial familiarisation with the data by reading and transcribing narrative. Notes were made during the transcription process as key concepts emerged. This was followed by a preliminary analysis of the entire set of transcribed responses, identification of concepts and a literature review to establish a thematic framework. Thematic categories were developed by considering each sentence, phrase or paragraph of transcripts in an attempt to summarise key concepts. The key issues and concepts expressed by the participants formed the basis of a thematic framework. Emerging themes were then discussed and agreed. Responses were indexed according to the established framework, then mapped and interpreted. The mapping was a manual process used to determine linkages between themes and overlapping concepts, which refined the framework and determined the final eight key themes. To establish rigor in this approach, all responses were initially analysed by one researcher, then independently categorised by a second researcher. Discrepancies were discussed with a third reviewer until consensus was achieved. Privacy rules governing the use of the NDSS dataset for participant recruitment, did not allow for respondent validation.

Data from the survey was coded and entered into SPSS version 15.0. Univariate chi-squared analyses were performed to determine variables associated with each theme. This quantitative component of the analysis was conducted by age group (above and below the mean), whether a language other than English was spoken at home, previous diagnosis of GDM, use of insulin, being Australian born, having a tertiary education & being overweight.

4. Results

Of women registered on the National Diabetes Services Scheme (NDSS) with GDM, 5576 had consented to be contacted for research purposes. Invitations were sent to 4098 women who met the inclusion criteria, with 249 women unable to be contacted. Of those invited, 1381 women returned surveys, indicating consent to participate (36% response rate). Nine ineligible surveys were excluded, resulting in 1372 eligible respondents. Of those, 393 (29% of respondents) completed the optional question about sharing their experiences with GDM. Free text comments ranged in length from a few sentences to several pages of narrative.

The demographics of question respondents was compared to those available for the entire NDSS dataset ($n = 15,893$) (Table 1). The women providing details of their experiences with GDM were slightly older ($p < 0.001$), more likely to be Australian born ($p < 0.001$) and less likely to have used insulin ($p = 0.009$) when compared to women registered on the NDSS.

From the narrative provided, eight key themes emerged from the data when women described their experiences with GDM with an additional cross-cutting theme of either giving or seeking information. Some comments expressed more than one theme and

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